

Spastics News

Happy Christmas to all our readers!



HRH The Princess of Wales is patron of the National Rubella Council.

### Campaign against Rubella

The Spastics Society has joined the Department of Health, the Health Education Council and ten other voluntary organizations in a national campaign against rubella (german measles).

Over the next three years there will be a concerted effort to increase the take up of immunisation by schoolgirls aged 10 to 14 and by women of childbearing age who were not immunised at school. The aim is to achieve at least 95 per cent immunisation among schoolgirls. In 1982 it was 83 per cent.

Speaking at the launch of the National Rubella Council in London on 29 November, Kenneth Clarke, the Health Minister, referred to the tragic handicaps rubella can inflict on unborn babies if the mother catches german measles in the first three months of pregnancy.

"As a result of the last epidemic (1978-9) at least 120 babies were born rubella-damaged and there were 1400 abortions associated with rubella infection," he said. "This is a tragedy which I believe we can prevent in the future."

The rubella vaccine is cheap, and is considered safe. The only people who should not have it are women who are pregnant or expect to be in the next 3 months, and a tiny number who have reduced immunity or are allergic to Neomicin or rabbits.

So far, the campaign consists of posters and leaflets, two short videos for use in schools, and a "rubella credit card", which will be given to everyone who has

been immunised or whose blood test reveals immunity.

The leaflets will be available in Bengali, Gujarati, Hindi, Punjabi and Urdu as well as English.

The Society expects to play an important role in the campaign. Dr. Nick Sidle (who remains head of the Hera Unit) is both a member of the National Rubella Council and one of its medical advisors.

As a result of research into the uptake of immunisation by schoolgirls, the Hera Unit has produced a rubella fact sheet and will soon have a rubella pack for schools.

"It is essential to provide information as rapidly as possible," says Nick Sidle.

He welcomes the appointment of a co-ordinator to the Council, Mary Welland. "A co-ordinator is needed to bring together the different representatives so that we can start the campaign as soon as possible," he says. 1983 has produced another rubella epidemic.

The Hera Unit is now working on another project. An informal survey carried out earlier this year revealed rubella-damaged children in second or third pregnancies.

"The mother's susceptibility to rubella should be identified in her first pregnancy and therefore the risks in subsequent pregnancies should be entirely avoidable," says Nick Sidle.

He hopes to find out how many slipped through the net and why, and then to make recommendations for additional efforts in health education and changes in clinical practises.

### Ups . . .

On 18 November the Tadworth Court Trust, a group of three charities led by The Society, came a step nearer to running the Children's Hospital.

Kenneth Clarke, the Health Minister, announced in a Commons written answer that "I have now authorised a settlement under which approximately 30 per cent of the total site will be leased to the Trust at a peppercorn rent."

The site, about 20 acres, includes the hospital buildings and the mansion, Tadworth Court.

The mansion has been a hub of contention in the last few weeks as the Board of Governors of the Hospitals for Sick Children, Great Ormond Street, have sought to prevent it being handed over to the Trust.

Tim Yeo, Chairman of the Trust, is delighted by the DHSS news, though he regrets the hold-ups.

He promises a full statement to Tadworth staff on 12 December.

"We expect to re-engage a substantial majority," he says.

### . . .and downs

There was great disappointment in the disability lobby when, after all the hard work, Bob Wareing's Bill failed to get a Second Reading.

It was not only Labour MPs who were angry when the Government wheeled out its payroll MPs to swell the "noes" while avoiding recrimination for imposing a Government whip.

Tim Yeo, John Hannam, Richard Body and Martin Stevens were brave enough to vote against the party line, though Tim Yeo's speech criticising the Bill for expense and partial irrelevance was seen by some people as a balancing act which could please neither side.

Since then the issues have been kept alive by a letter to *The Times* from 14 voluntary organisations, signed on behalf of The Society by Mrs Joyce Smith, and by MPs continually raising points of order in the House.

Now Lord Longford has introduced the Bill into the House of Lords. He hopes to get time for a Second Reading before Christmas.

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### Their achievement, our challenge

David Cook, winner of the 1983 Achievement Award, and Mrs. Sara Jones, widow of Colonel "H" Jones.

Finalists for The Society's 1983 Achievement Award gathered in London on 10 November to receive their medals and to hear the announcement of the first, second and third prize-winners.

The competition is an annual event for which friends and relatives enter children who have shown particular courage in overcoming disability.

"The competition brings home to people some of the difficulties so many young handicapped people have faced and overcome," said Dafydd Wigley, MP for Caernarvon, who was one of the judges.

"I hope the achievements of these young people will be an inspiration to others - both disabled and able-bodied. Their achievements underline the need for integration into the community of all disabled people, not only for their own benefit, but for the benefit of all of us," he said.

The other judges, who both

attended the presentation, were Colin Cuillimore CBE, Managing Director of Dewhursts who sponsored the event, and Sara Jones, widow of Colonel "H" Jones.

(Pictures and prize-winners, page 6)

### Out go BATs

The Society will sell its shares in BAT Industries. The Executive Council made this decision at its meeting on 18 November.

The 15,000 shares, worth around £97,500, were the subject of some heated comments at the AGM in October. To many people it seemed morally inconsistent that The Society should be making money out of tobacco while strenuously campaigning against smoking, a known contributor to handicapped births.

(Report of meeting, page 5)

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## THE DIRECTOR

## His final word

Instead of writing a farewell column, Tim Yeo talked to Mary Wilkinson about his last three years and the future.

**MW:** What do you think has been achieved in just over three years?

**TY:** Well, the financial situation has been transformed. The year I came we had just announced a deficit of over £800,000. Last year, as you know, there was a surplus very much in line with our budget. The reserves have been built up. It's something that many people have taken part in on the fund raising side and on the spending side, and it's been achieved at a time when other charitable organisations have not always been doing so well.

Then I believe The Society is much better known than it was four years ago. People now often look to us for a lead in giving a response for the disability community. Another big theme over the last year or two is the influence of consumers within The Society and indeed a greater sensitivity to consumer feelings and interests in the whole of The Society's operations. And lastly, staff morale is now higher; the staff of the central society are pulling together extremely well. Where I think more cohesion is needed is between the central society and the local groups.

**MW:** Do you think you have managed to change public attitudes to CP?

**TY:** I think we've made a start. One way we can do it is by accelerating the process of integration at every level. Another is through our advertising campaigns. I think it's a positive sign that we are willing to spend money on advertisements aimed exclusively at changing attitudes to handicap, and there's no evidence that it is affecting our income adversely.

**MW:** But on one side you have an advertising department that is consciously trying to change attitudes, and on the other an appeals department that sends out letters saying "Please help spastics".

**TY:** We have to face up to the dilemma. We have changed the advertising policies, for example, by refraining from using the most emotive language and pictures in our appeals work. I think we should continue in that way because The Society needs to educate the public about what it is like to be handicapped and to do that we've got to portray an accurate picture. I would like to see the phrase "help spastics" phased out completely.

**MW:** Some people would say that your emphasis on campaigns has been at the expense of services to the cerebral palsied.

**TY:** It's true that a lot of emphasis has been put on campaigns. But at the moment we spend less than 10 per cent of our annual expenditure on campaigning and that reaches a wide area of the population. The services consume 90 per cent of our expenditure and help perhaps 10 per cent of CP people in this country. So if I was going to be here any longer I would want to spend more money and more effort on campaigning.



"I've worked harder here than I've ever worked before."

**MW:** Have there been any failures in the last three years?

**TY:** There are some things we haven't yet done that we need to do. We need to develop The Society's long term planning, to sit back and think where does The Society want to be in the 1990s and how do we get there. We need to broaden out some of our campaigns. On employment, for example, which is one of the greatest concerns to adult CP people, we need a much more coherent policy. There is also great potential for a big voluntary organisation to tap the resources of the Common Market: we've only just started.

**MW:** What about the rejuvenation of local groups?

**TY:** We would like to see new groups developing. We've got to forget the structures we've had in the past and concentrate on helping self-help groups, with roving members of staff giving encouragement and information about local services.

**MW:** What about work centres? There seem to have been missed opportunities in marketing and perhaps some of our designs could be improved.

**TY:** We need to be as customer orientated in our work centres as we are trying to be consumer orientated in The Society. There have been interesting developments in our work centres as we showed in the film. Internal organisation is only part of the battle, though, because marketing is also very important.

**MW:** Do you think cerebral palsied people should have more influence in The Society?

**TY:** Certainly I would want to see greater influence exercised by cerebral palsied people. I was delighted when it was agreed to give the National Consumer Group some money of its own. Once you've got some budget and you can appoint staff and tell them what to do you have the opportunity to exercise more power.

**MW:** Should The Executive Council be composed entirely of CP people?

**TY:** No, that would not represent an integrated organisation. I would like to see each Council candidate given the chance to make a statement about themselves and their beliefs. That might or might not increase the number of CP people but it would produce a better informed election.

**MW:** The Society is not really geared to CP employees, is it?

**TY:** Again, we have just started to break the ice. The Society needs as a matter of priority to ensure that all its buildings are accessible to physically handicapped people. It is an issue on which we should be campaigning.

**MW:** How far should voluntary organisations supplement statutory services?

**TY:** The traditional roles of voluntary organisations are right and should be developed. Where there are constraints on public spending so that central and local government are having to defer the introduction of new projects, the question arises, should The Society and other voluntary organisations step in and provide these resources? I think we can be pragmatic. We should not be hidebound by any philosophical reluctance to do something which might be thought of as a statutory obligation.

**MW:** So we stepped into Tadworth. A discussion group at the AGM felt that Tadworth had given The Society a bad image, whereas VAT had given it a good one.

**TY:** There is overwhelming evidence to suggest that Tadworth gives us a very good image. We've had a lot of media coverage and The Society was associated in the minds of the public with an organisation which stepped into exercise a caring role when others did not. Correspondence has run overwhelmingly in favour of our involvement. And I think it is no coincidence that the Christmas appeal last year resulted in record donations. VAT is a much more controversial issue because you could argue that to complain too loudly about VAT might deter people from giving money - to VAT. But we should continue to be involved and I shall certainly continue to be involved myself.

**MW:** How have you seen your job as Director?

**TY:** Well, I've always believed in leading from the front. In a voluntary organisation you have to be prepared to appear before employees and voluntary supporters very frequently and justify in public the policies of your organisation in a way you wouldn't expect to do in a commercial climate. It's a job that requires particular qualities of management because people come to The Society for all sorts of reasons. One of the problems is that The Society is a lateral organisation, not a pyramid. The Director is expected to deal direct with a wide range of people and issues. We are also a diverse organisation in our range of activities, probably uniquely so among British charities. The Director has got to have some kind of response on a colossal range of subjects. From that point of view it's more like politics than running a business.

**MW:** What about the Director's relationship with the Executive Council?

**TY:** It's critical. I was lucky when I first came because I had tremendous support from the Council for what I wanted to do. In the first 4 weeks, for example, we abolished the Public Relations and Fundraising Committee and since then the fundrais-

## Letters to the Editor

Spastics News 12 Park Crescent London W1N 4EQ

## Positive parent

I was irritated today when I read Bill Hargreaves' "Warning to Disabled Parents" (*Spastics News* October), since being spastic myself I am concerned that we should abandon all deferential attitudes to society at large. In a world which could be heading toward a nuclear holocaust, it seems ironic to me that we should be so concerned to protect our children against the less savoury side of human nature.

You might just as well argue that since the world is a risky place no one has any right to bring children into it, as "The ability to counsel their future children about how to cope with the prejudicial remarks of the ill-informed should be a deciding factor in the question of whether spastic people should consider having children".

Surely we would not counsel a black couple not to have children because of the fact that those children will have to tolerate the uncensored remarks of those whom our society has not taught to know better?

Like Bill, I went to an ordinary school and put up with a lack of understanding from other children. Also, like Bill, at 43 I still stagger and fall. Yes, it is embarrassing and annoying, especially when you wear the knees thin on an otherwise good suit.

These, then, are some of the negative features of a disability like ours. However, since we cannot choose not to be spastic, we may as well look for what's positive about it.

1. Being spastic has forced me to question life at a deeper level than I might otherwise have done.

2. Others around me, e.g. school friends, have experienced another facet of what it is to be human and humane.

3. Being physically constrained has helped me to make the most of what resources I have, both obvious and hidden.

I like to think, and the evidence so far confirms this, that my wife and I are bringing up well-adjusted youngsters who will benefit from some of the positive consequences mentioned above, without having to suffer the physical constraints.

**Ian Hirst,**  
183 Counthill Road,  
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ing has increased faster than at any time in The Society's history.

From my own experience I would say it was easier to make changes in the first 18 months. The longer you are here, the more you get hedged about by knowing the pressure groups and vested interests, and the less you want to upset people.

As to my relationship with the Council, I definitely wished to involve myself with the making of policy. In The Society, power surges from the Council to the staff and back again. Before I came, a lot of power had gone into the Executive Council, and so a priority for me was bring that power back to the staff. I think the Council has been concerned that I and the other directors have decided too many things in the last year or so.

**MW:** Now that you are in Parliament, some people will see you as The Society's spokesman.

**TY:** I don't see myself that way at all. I'm there to do my best for my constituency and the Con-

## Be angry!

I was appalled to read Margaret Morgan's reply under the heading "Angry young man" in September's issue of *Spastics News*. People with a severe communication problem have a right to be angry with other people's indifference. For Ms. Morgan to refer in this context to behaviour modification and lack of maturity is in itself disturbing behaviour.

Technology in the form of communication aids is not the answer in every case, but in a column which is for general consumption a mention should have been given to this topic. A valuable source of advice is Roger Jefcoate, an independent consultant on technical aids for people with disabilities. He can be contacted at Willowbrook, Swanbourne Road, Mursley, Bucks, MK17 0JA.

**Peter Head,**  
8 Dorncliffe Road,  
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## Black day

Friday 18 November must surely be remembered by disabled people as one of the blackest days in the history of this parliament, following the defeat of the Chronically Sick and Disabled Persons Amendment Bill.

This proposal was supposed to have been a private members' bill, with MPs free to vote as their consciences dictated, irrespective of party allegiance. To find that this attempt to update legislation to improve conditions for disabled people was set to be defeated long before the debate, on account of instructions to some members, was greeted by anger and dismay to all those who, like me, attended the Anti-discrimination Conference at Westminster Cathedral Hall.

This may be the reason why I received the courtesy of an acknowledgement or reply from only two of the seven MPs representing Leeds, (one Socialist, one Liberal), after I had written to them.

I understand that the Minister with responsibility for the disabled has said that he is sympathetic, but that the disabled must rely on "goodwill and per-

*Continued on page 3*

servative Party. I hope I will be able to deal sensitively and sympathetically with issues which concern The Society. But there is no doubt in my mind as to where my first loyalty lies. The Society needs voices in all parties and, indeed, it has already built up many relationships.

**MW:** What impact has The Society had on you?

**TY:** I have had an opportunity to run a large organisation which operates in a completely different way from a commercial one. I've learnt all sorts of things about the handling of people. I've had the opportunity to negotiate with civil servants and ministers. And, of course, I am far more aware of disability than I would have been otherwise.

Though I have worked harder here than I have ever worked before, I've enjoyed it more than any job I've ever had, and I shall depart with great sadness. It is only because I am going to do something I have wanted to do all my life that I am able to leave at all.



## Letters to the Editor

Continued from page 2

suasion". This is pathetic, and merely evades the issue. "Goodwill" often evaporates when disabled people are offered rights rather than solace, and why should they have to depend on goodwill more than others, in order to enjoy choices and opportunities others take for granted?

As regards "persuasion", how does one change an obstinately held misguided belief? It is too naive to suppose that the habits and attitudes of a lifetime can be swiftly changed through education and persuasion alone. How does one educate the apathetic and indifferent?

**William Higgins,**  
Chairman, Leeds and District Spastics Society

## Drinking straw

We were interested to read Rosemary Dawson-Shepherd's letter (*Spastics News*, September) drawing attention to the difficulties disabled people can experience as a result of choosing an inappropriate aid or piece of equipment on the basis of the manufacturer's description.

Although Aids Centres cannot carry out systematic evaluation of equipment, they can pass on comments to organisations set up to do this such as the Aids Evaluation Information Group, the Institute for Consumer Ergonomics and the DHSS Aids Assessment Programme.

Rosemary Dawson-Shepherd's experience with the Pat Saunders Drinking Straw is an interesting example of how an aid which is no doubt very useful to many disabled people, may not be particularly suitable in the case of cerebral palsy.

**Rosalind Doig**  
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## REPORTS

### Benefits Conference

#### Ironing out the differences

125 delegates representing a wide range of organisations concerned with disabled people attended The Spastics Society Disability Benefits Conference at Westminster Conference Centre on 3 November.

The main aim of the conference was to win agreement on a Comprehensive Disability Costs Allowance and Income Scheme.

During the morning, Tim Yeo (The Society), Alan Walker (The Disability Alliance), Peter Large (The Disablement Income Group) and Peter Mitchell (RADAR) outlined their preferred schemes.

While The Society's scheme won considerable support, there was also constructive criticism.

After lunch people joined different workshops to discuss difficulties in the present benefits system and how best to overcome them.

"Faculty or function?" (Alan Walker) produced a fairly heated discussion on the best way to measure someone's disability. "Sick or fit?" (Peter Mitchell) considered partial incapacity benefit. Amanda Jordan led "Getting the message across" — methods of campaigning for the rights of disabled people. Nick Morris from the Institute of Fiscal Studies led a discussion on how a scheme could be funded, and Caroline Glendinning explored "Women and Disability."

The day was a success. The major disability groups are now keen to work towards a consensus; disagreements have been aired and to some extent resolved.

Summing up the day's proceedings, Tony Lynes, the chair-

man, proposed setting up a working party. This will produce a scheme supported by the Disability Lobby which can be presented to the Government.

Pip Evans

### Anti-discrimination legislation conference

#### The bubble bursts

The culmination of the summer's anti-discrimination conferences came when 230 people arrived at the Westminster Conference Centre on the day before the Commons debate on the subject.

A sense of urgency and purpose prevailed throughout the day. Whether, in the light of the result of the Commons debate, that sense of purpose was fulfilled or frustrated is impossible to discern.

The Chairman, The Society's Director Tim Yeo, opened the agenda by briefly outlining the topic to be discussed. He then handed over to Ron Gerver, Chairman of the Society's Consumer Group, who gave an assessment of previous conferences and examined the various laws in other countries which have precedents for the proposed bill.

The Chairman introduced a panel of disabled people: Peter Large, Barney Wilson, Steve Bradshaw, Sharon Hughes and Sue Maynard. Questions were invited from the audience.

I was struck by the persistence of the political realization among the questioners, which, though extremely relevant in my opinion, was nevertheless firmly controlled by the Chairman. Admittedly, the political points might have been seen as more appropriate for the following discussion with the panel of MPs, and some of the points were not strictly relevant to anti-discrimination legislation, but

for me the whole point of legislation is political, and no one should have attempted to avoid this.

In addition, since most delegates came with a firm knowledge of the topic and many had actually read the proposed bill, discussing the minutiae of the legislation seemed like going over the ground already covered in previous conferences, and in any case, changes in the proposal were not possible.

After lunch we were joined by five parliamentarians. It became crystal clear during the introductions how utterly convinced the audience was of its cause. The four advocates for the legislation were heartily cheered and the ex-minister was simply politely applauded. This set a pattern which prevailed throughout the remaining discussion whereby Messrs Morris, Wigley, Meadowcroft and Wareing were openly acknowledged as emphatic champions and Sir Hugh Rossi obviously had something of a credibility gap.

The discussion seemed all too short and Tony Newton did not appear as hoped. Twenty-four hours later it became obvious why he probably thought it unwise to attend.

I began by mentioning that there was a sense of purpose which may perhaps have been frustrated. If this was so, it could have been because everyone was already aware before the meeting, of a newspaper report about the Government whip to be used in the voting lobby the next day. Yet no time at the conference was allocated to discuss possible scenarios for the failure of the bill. Even given no such whip, the minimum requirement of 100 supportive votes may not have materialized, or the Government could have made a token gesture and given it a second reading. In other words, even if deliberate Government action had not killed the bill there were ways in

which it would not have reached the statute books — and yet these possibilities and their consequences were left undiscussed.

There now remains a vacuum. Consciences have been awakened and even given the events in the Commons they must not be allowed to atrophy.

This cannot be the end, but the beginning.

Chris Davies

### Micro-technology and special education

#### All in a day

A presentation designed to show leading educationalists what can be achieved in special education using microtechnology was held in Bristol on 21 November and opened by HRH Princess Anne.

The presentation was sponsored by the Department of Education and Science through its Micro-electronics Education Programme. Over 25 per cent of the country's chief education officers attended.

Both normal schools and special schools were represented. It was interesting to see how they have applied microtechnology.

St. Francis School in Lincolnshire demonstrated a writing aid for severely physically handicapped children which is operated with a switch and designed for use with a BBC computer.

Crownbridge Special Day School in Gwent has introduced micro-electronics into the classroom with modified and reconstructed toys used as stimulating education aids.

While it was clear how some developments in mainstream education can be applied to children with special needs, it will be interesting to see if the reverse is true. Will the extensive use of colour, sound and graphics in special education be equally useful to ordinary primary schools?

Barry Hassell

## You only pay twice!

Linda Avery shows how the new "energy tax" affects disabled people

The age of cheap fuel in Britain is long past — even though we live in an energy-rich environment and international energy prices are falling. The outcome of this year's public expenditure review shows the Treasury having won a controversial battle over public spending, against the Department of Energy and most of the other big spending ministries.

It also shows a government which is no longer prepared to pay even lip service to the idea of a coherent energy policy.

The Treasury is to be allowed to impose financial targets on the gas and electricity industries which will result in a 5 per cent increase in gas prices from January, and a 3 per cent increase in the price of electricity from April. That little victory means the treasury will reap £600 million with which to fund the Exchequer.

So who are the losers? Certainly the Confederation of British Industry will be less than pleased, because Britain's energy-intensive industries — chemicals, steel, paper — already pay 20 per cent more than most of their European competitors.



Higher fuel prices increase costs, and therefore prices. This leads to a reduction in demand for our goods which does little to ease unemployment.

More important, what of the domestic consumer? British Gas has already reported a substantial increase in customers' requests for time to pay; the electricity boards currently have in the region of 1,500,000 customers paying via a monthly budget payments plan.

Every winter we read of unemployed people, single parents and families on low incomes who have had their fuel supplies disconnected and who are forced to survive the winter months without any adequate form of warmth or cooking facilities.

At the end of every winter there is the sad count of elderly

people who have died from hypothermia rather than run the risk of heavy bills which they know they will never be able to pay.

But what of the doubly disadvantaged, those disabled people who because of their disabilities are likely to need increased warmth and more energy (as opposed to fuel), and have to rely on state benefits or very low incomes?

It is widely accepted that sickness and disability increase the cost of living and that heating is one of the main culprits. Relative immobility creates poor blood circulation leading to a greater need for warmth; some form of heating may even be necessary during the summer months. Washing and dressing often take a disabled person far longer than an able-bodied person.

Most of us enjoy warm working conditions paid for by our employers; a disabled person who is unable to work or who works at home will be forced to keep the heating switched on, and unless that person is confined to one room 24 hours a day, almost all the other rooms in the household must also be kept warm.

State benefits to assist with fuel costs are restricted to those claiming Supplementary Benefit (SB) or Family Income Supplement; but those whose income is from such sources, or from low paid or intermittent work, can rarely afford to instal the most cost effective heating systems. Nor are they necessarily able to afford the most economic methods of pay.

In any case, the regulations governing, for example, additional heating allowances — and the amounts of financial assistance available — are neither geared to meet the special needs of disabled people, nor are they adequate.

Take-up amongst this group is known to be low. Ignorance regarding entitlement on the part of the claimant, combined with a lack of sensitivity to their special needs on the part of SB Offices, often means that disabled people do not receive even this limited assistance. Many others, despite low incomes, are not entitled to SB.

A further problem is that people with disabilities often face higher bills for their energy consumption because they have to rely heavily on electrical appliances such as washing

machines, tumble dryers, water heaters, power lifts and hoists. Then there are the electrically operated respiratory or dialysis equipment and patient operated selector mechanisms by which severely disabled people can exercise some control over their environment.

Disability, low-incomes and continually rising energy prices all combine to keep disabled people caught in the trap. But the Whitehall manoeuvrings go on.

Gas and electricity have long been recognised by chancellors as useful sources of revenue when the financial going gets rough, yet Nigel Lawson denies this. He argues that gas and electricity should be priced at economic levels both in the interests of equalising the two and in the interests of efficient use of fuel — consumers will save energy if the price is pushed up.

Peter Walker, Energy Secretary, who publicly opposed the increases, argued that the price rises amounted to an energy tax on consumers which was wrong in principle.

The London Electricity Consultative Council has suggested that the time is fast coming when consumers will have to test the legality of government price-fixing.

In the meantime, disabled people are more likely than others to experience difficulties in paying bills and to suffer disproportionately if they have to economise or pay substantial amounts towards outstanding arrears. They are double losers to the energy tax.



## INTERNATIONAL



## Ayse Araldi

## "It's all do-it-yourself!"

"You'll be frustrated when you go back", Dr Ayse Araldi was warned by the principal of a residential school last month.

Ayse, a physiotherapist from the Turkish Spastics Society, was over here on a fact-finding tour organised by Cerebral Palsy Overseas. She laughed. "I might", she said.

The thought had not occurred to her before. Enthusiastic and overworked - The Society has 4,000 registered patients - she does not think in those terms.

She is more concerned about how best to help a family she may see for only a few sessions.

Looking at the English centres from this point of view, many seemed to be locked into one form of therapy. "Every group clings to their own methods and thinks that is right," she commented.

Working so much with mothers, she was naturally impressed by Conductive Education. But she had doubts about whether she could make it work. "I don't have that much control over my patients or see them often enough", she said.

Ayse holds a PhD in physiotherapy. For six years she taught clinical neuro-anatomy at

Hacettepe University in Ankara, which has the only physiotherapy school in the country. To help train the students she and others started a cerebral palsy unit and then a workshop.

It was only when her family had to move to Istanbul that she met Professor Hifzi Ozcan, founder of the Turkish Spastics Society. "He kind of brainwashed me into working for him".

For the last four years she has been the only physiotherapist, with a steadily increasing workload. Besides helping with assessments, she runs group therapy sessions for mothers and children as well as offering individual help and visiting local mother-and-baby centres. She also runs a second-hand aids service and liaises with a local man who makes equipment. "It's all do-it-yourself," she says cheerfully.

The Society tries to get physically disabled children into normal schools and mentally disabled ones into special classes. It is in touch with local education authorities all over Turkey. But there is little available for severely handicapped children.

Inevitably the question arises, what happens after school? The Society would like to have a workshop of its own. Rug making has been started and so has ceramics. "We train ourselves and then pass on the knowledge," says Ayse. Mothers are told to do the same thing, but there is little evidence that the advice is taken, and there are no local groups to offer support.

Since its services are free, The Society survives mainly on donations and fund-raising. The Turkish Ministry of Health pays some salaries, including Ayse's, and helps with running costs.

Plans for expansion on some adjacent land are held up for lack of funds.

At present space is so limited that when Ayse is not using her therapy room the sports group moves in, with strict instructions to remove their shoes before walking on the fitted carpet.

Last year 4 athletes won 5 gold medals at an international event.

From little acorns...

Mary Wilkinson



Istanbul is one of the most beautiful cities in the world.

## Turkey

Derek Lancaster-Gaye finds out how you cope with 4,000 patients in one converted villa.

Viewed from almost any angle Istanbul is a remarkable place, half in Europe and half in Asia, with the cultures of each happily merged and reflected in its architecture, its food, its dress and its language. Add to all that the Bosphorus and the Marmara Sea and you have what must be one of the world's most beautiful cities. Judging from local pride I suspect that 50 million Turks share this view.

My trip to Turkey was part of a series in the Eastern Mediterranean, and as usual I was in search of information about cerebral palsy and other disabilities.

Time is always at a premium, so my visit was confined to Istanbul at the extreme western end of Turkey. This is the home of the Turkish Spastics Society which has had a relationship with the UK Society since it was formed in 1972.

Some services do exist in Turkey for a wide and rather indiscriminate range of physical and mental handicaps. Some are in the hands of the Government; others are provided by voluntary agencies.

Compulsory education, for example, includes the physically

handicapped, though special education is not a feature of the Turkish educational system. Indeed, there are very few special schools and those are mainly for the deaf and dumb and the mentally handicapped.

The theory is that all handicapped children go to ordinary schools. Certainly many schools are geared to cope with wheelchairs, and the concept of integration is practised through special classes. There are around 500 such classes in Turkey.

The reality, however, is that cerebral palsy is too difficult for many of these classes - there are only six teachers in Istanbul with special education training - and the classes are not always in the right place. Given problems of transport, many CP children do not go to school.

Special equipment and physiotherapy are in short supply. There is no speech therapy.

I had the impression that any specialised services and an understanding of cerebral palsy were limited to perhaps three centres. One of these, and by far the most specialised, is run by the Turkish Spastics Society.

With a recorded case load of

nearly 4,000 cerebral palsied people and a moral responsibility for the whole of Turkey, the Society has an almost impossible task if it is to make any significant impact on the CP problem.

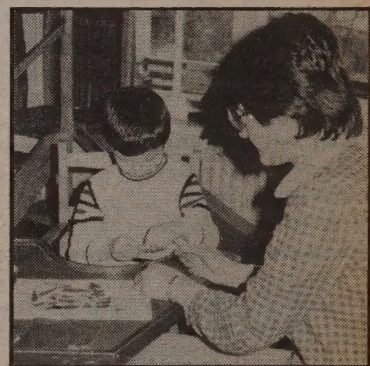
The centre is a converted villa on the Asian side of Istanbul which provides a daily service on demand. Clinical services in neurology and paediatrics are in the hands of Professor Hifzi Ozcan, founder and Chairman of the Society; physiotherapy is organised by Dr Ayse Araldi, alone.

Coping with 4,000 patients single-handed does have certain implications. Regular treatment at the centre is simply not possible, as it is a matter of teaching the parents fundamental therapy in the hope, but not necessarily the expectation, that treatment will be continued at home. The high cost of travel and the evident limitations of public transport ensure that the children attend sometimes as infrequently as once in three months.

The centre has eight paid staff members and an army of volunteers whose prime role is finding the cash to keep going.

Generally speaking, disabled people are not organised in Turkey. However the Turkish Spastics Society has become involved with Special Olympics. At the time of my visit a group of young people was training for the 1984 event in the USA.

I suspect this was all due to the enthusiasm of Professor Ozcan without whose imagination and backing many of the CP activities in this part of the world would not have happened.



One-to-one, but there are 3,999 others.

## ICPS

It has been pointed out by Mrs Anita Loring, Secretary General of ICPS, that her husband, James Loring, has retired as President of ICPS. He did not resign as stated in "A Trip to Gothenburg" last month.

Honorary officers for the coming year are: President, Ciaran Barry MD (Republic of Ireland); Vice President, Mrs Ethel Hausman (USA); Honorary Treasurer, Arie Klapwijk MD (Netherlands).

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## CASTLE PRIORY

Effective health education, child rearing and care of handicapped people depends on communication. This is difficult enough among our own population; the barriers of language, culture and religion add to the problem.

There are three main groups of Asian immigrants in Britain: Hindus, Sikhs and Muslims. Most of them came originally from rural areas in the Indian sub-continent, but those from East Africa came from urban areas and commercial backgrounds.

Any family that has a young handicapped child faces lack of sensitivity or over sensitivity to disability. Asian families suffer perhaps more, because the child, particularly the son, is the sign and show piece of a marriage.

The Hindu concept of Karma (deeds of the past) has a familiar ring to Western ears, "Where in my Karma have I gone wrong?"

To overcome cultural barriers the professional worker or friend needs to know about the religious laws and local customs of a family because these effect its willingness and ability to accept advice. It is possible to unwittingly offend, abuse rules of hospitality, or compound the worst fears of traditional Asians about our values.

Also, professionals should try

## The handicapped child in the Asian community

Rosemary McCloskey has run two courses for Asian and Caucasian workers at Castle Priory College, Wallingford.

to penetrate the language barrier. Communication through an interpreter is likely to cause problems.

## Form of address

We in Britain have a complex but clearly understood naming system. We all know exactly the attributes of Mrs, Mr, Miss, forenames, Christian names, surnames, and so on. But each Asian group has a different naming system and they all differ from the British system. Where this is not understood, pregnant women attending antenatal classes or mothers attending clinics are subjected to undignified muddles, delayed treatment, frustration and stress.

## Child rearing

In general we are ignorant about child rearing practices outside our own. Asian children are cared for by all the women and by elders, brothers and sisters. The baby is carried by its mother most of the time and suckled whenever it cries, in the belief - not confined to Asians - that to allow a child to cry weakens it.

Attitudes towards toilet training are similarly varied and until a child is about five everything is done for him - washing, dressing, feeding. So the whole

concept of independence programmes may be foreign.

The implications for therapy are evident. While professionals at school may be working towards improved positioning for speech, feeding and function, at home the programme may be undermined. A child may eat in a different position and use his fingers. Among Muslims, the right hand is clean and used for eating, the left for cleansing.

## The family

The extended family is the centre of all Asian cultures and has a very strong influence on behaviour and outlook. The individual is subordinate to the family.

If an "outsider" talks about a child or admires it unduly, the traditional Asian holds an evil force responsible for any misfortune or illness which subsequently befalls the child. It is therefore better to avoid commenting on the assets of a handicapped child until there is a firm and trusting relationship.

Many misconceptions occur because of close family ties, particularly among school children where there is no equivalent to "cousin"; every male within the extended family is addressed as

brother or uncle.

The concepts of relief or short term care are foreign to people whose life is centred around a family network. Husband and wife have no model for using time off from their children.

The anxiety in any family to improve or alleviate disability can tempt parents to try unorthodox treatments. Asian families are no exception, so a child undergoing a regulated programme at school may be following a separate regime at home or in the holidays.

Alternatively, some families accept the handicaps as "fate".

## Training must improve

While residential staff and others still lack knowledge of cultural and religious differences and special needs, there are signs of innovation in the services to elderly Asians.

Ignorance is not so much a matter of individual neglect as of institutional failure to provide training which takes account of ethnic differences. However, institutions will not change until there is pressure from informed people both Asian and Caucasian. "What is my attitude?" should come before "What can be done?"



## EXECUTIVE COUNCIL

### Beech Tree is brought to heel

**Beech Tree House.** The Society's unit for severely disturbed children in Hertfordshire is to revert to the control of Meldreth Manor.

At its meeting on 18 November, the Executive Council endorsed the policy laid down in 1977. This will take effect from January 1985 when the new unit opens.

It is hoped that children from long stay hospitals will continue to go to Beech Tree but they will be cerebral palsied children, who can move on to Meldreth.

**Wilfred Pickles School.** Approval was given for the sale of the school at whatever reasonable price over £450,000 would meet the Charity Commission's criteria.

**St Margaret's School.** Parents are trying to rally support from The Society to keep the school open. The Society is not directly involved except as a landlord charging a peppercorn rent. Mrs Smith and John Belcher will be meeting governors and parents on 14 December.

**Scottish Council.** The meeting between the Executive Council and members of the Scottish Council was postponed.

**Collection boxes.** A working party has been set up to look into the whole operation.

**Residential care.** The Council has asked for a report to be submitted by autumn 1984 which will propose a new policy for residential care. It will take account of recommendations from the Living Options Group.

**Progress reports.** These were received from the working party on Employment and from the Living Options Group.

**Disciplinary procedure.** Approval was given to the formation of an Appeals Panel consisting of the Director, the Chairman and two members of the Executive Council. It will provide the final level of management for any appeal against dismissal.

**Spastics News.** A discussion of the newspaper was deferred until January.

**New appointment.** A Technical Controller is to be appointed.

**Council appointments.** Dr Millicent Regan and John Byworth will replace Mrs Eileen Milnes and Peter Rigby on the Management Board this year. In future, the three places not taken by Honorary Officers will be filled by different members of the Council on a rotating basis.

Present members of other committees were reappointed and representatives on the various management committees were approved. Sir John Cox will replace Tim Yeo as the Council's representative on the National Council for Voluntary Organisations; Stephen Williams replaces Richard Gray on the Riding for Disabled Association; and John Belcher was appointed as the Council's representative to Habinteg.

**Arrangements** for next year's AGM were approved. It will be held on 3 November, starting at 10.30 am. During the morning there will be time for questions, and in the afternoon after the group meetings there will be a plenary session.

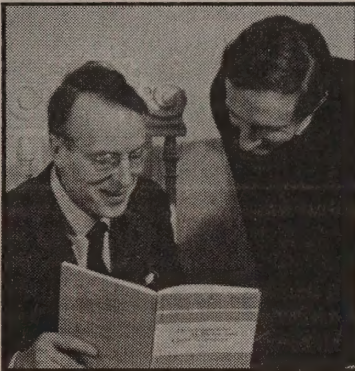


In 1958 the late Dr Ronald Mac Keith persuaded The Spastics Society that a useful way to improve the health services for cerebral palsied children would be to promote the publication of a medical journal, *Cerebral Palsy Bulletin*.

Ronnie Mac Keith was a man of ferocious energy: the journal developed and expanded rapidly.

In 1961 I joined another doctor, Dr Edward Clayton-Jones, as Assistant Editor. One of my first tasks was to try and sort out a relationship between The Spastics Society and the young journal. Ronnie Mac Keith spent money first and told The Society afterwards. Nor did his ideas always go along with those of the directors of The Society.

He saw, rightly, that to get



Ronnie Mac Keith and Martin Bax celebrate their impudence.

doctors who worked with children with cerebral palsy to read the journal, it would have to cover a broader field and so he pushed through the change of name, from *Cerebral Palsy Bulletin* - which The Society liked - to *Developmental Medicine and Child Neurology*.

At the same time he started a series of books now known as

*Clinics in Development Medicine*. These again went to press without any warning to The Society that he expected it to pay the printing bills.

All this hectic activity led to a series of monumental rows. Ronnie Mac Keith, who was so patient with a cerebral palsied child and his family, was known for his quick temper in committee. Once, at a directors meeting at The Spastics Society, the late Professor Neale (then Chairman of our Editorial Board) and I had to physically hold Ronnie down to prevent him walking out of the room.

Eventually, however, a sensible agreement was hammered out with The Society which guaranteed the journal's scientific independence but recognised The Society's key role in supporting it.

Other early excitements came with the development of international connections.

We arranged to meet the American Academy for Cerebral Palsy, a group of physicians who included such famous names as the late Winthrop Phelps and Meyer Perlstein.

Our initial meeting with the Academy was somewhat hair-raising, because it was set for Dallas, and Ronnie and I and the late John Kershaw flew in on the evening of the day President Kennedy had been shot. Not an auspicious beginning for an Anglo-American relationship.

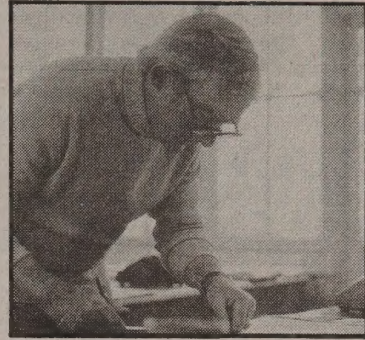
In fact our American colleagues were so shaken by the assassination that they were relieved to get down to something else, and we spent three hours that evening thrashing out the details of a relationship which has been sustained for 22 years. The Academy later adopted our

## Martin Bax remembers 25 Years of SIMP

# The day we went to Dallas

journal as its official organ.

Now 25 years later, the journal and the books are well established. The journal has been re-



Bernard Hayes, Managing Editor of the journal.

designed for its 25th year but still has its bright red cover. Many of the articles are very technical, but we try to give a doctor practical information too. Our August issue, for example, discussed the early use of powered wheelchairs by very young children, and our October issue asked a group of parents to assess a study made of

booklets about cerebral palsy that were designed for parents.

The red books, *Clinics in Developmental Medicine*, have gone on developing. Many authors are keen to publish with us, such as Karel Bobath, author of the standard work, *A Neurophysiological Basis for the Treatment of Cerebral Palsy*. Our next book is a study in the epidemiology of cerebral palsy.

The Chairman of the Editorial Board is Professor Ross Mitchell from Dundee, and the other editors are Dr Henry Baird, a paediatric neurologist in Philadelphia, Professor Kevin Connolly, a psychologist in Sheffield, Dr Keith Brown, a paediatric neurologist in Edinburgh, Dr Aidan Macfarlane, a consultant paediatrician in Community Health at Oxford, Bernard Hayes, Managing Editor, and Dr Sue Jenkins who, like me, work in London.

25 years from now we hope we will still be doing our bit to try and improve the health care of people with cerebral palsy.

## Can you help?

The Society's Working Party on Employment Provision for Disabled People wishes to conduct a survey on the occupations and activities listed below.

If you are a disabled reader of *Spastics News* and would be willing to answer questions about your work, please tick the appropriate box (or boxes), print your name and address in the space provided, and return the slip in an envelope addressed to The Spastics Society, Freepost 5, London W1E 4QZ. No stamp is needed.

Open employment <input type="checkbox"/>	Youth training scheme <input type="checkbox"/>
Co-operative <input type="checkbox"/>	Commune <input type="checkbox"/>
Adult training centre <input type="checkbox"/>	Occupational therapy <input type="checkbox"/>
Industrial unit <input type="checkbox"/>	Training <input type="checkbox"/>
Work centre <input type="checkbox"/>	Further education <input type="checkbox"/>
MSC Community Programme <input type="checkbox"/>	Professional workshop <input type="checkbox"/>
Industrial oases <input type="checkbox"/>	Work experience <input type="checkbox"/>
Job sharing <input type="checkbox"/>	Reciprocal care (helping each other) <input type="checkbox"/>
Voluntary work <input type="checkbox"/>	Homework <input type="checkbox"/>
Sheltered workshops <input type="checkbox"/>	Independent home management (housewife) <input type="checkbox"/>
Sheltered Industrial Groups (SIGs) <input type="checkbox"/>	Creative unemployment <input type="checkbox"/>
Part time work (open employment) <input type="checkbox"/>	Leisure <input type="checkbox"/>
Self employment <input type="checkbox"/>	Distance learning (e.g. Open University) <input type="checkbox"/>
Horticultural workshop <input type="checkbox"/>	Community work <input type="checkbox"/>

Name .....

Address .....

## Someone to speak for them

Some of the most isolated people in our society are those who live in mental handicap hospitals and have no relatives or friends outside. They lack anyone who will speak for them.

The problem was recognised in a review of the Mental Health Act published in 1979. "The most important factor in safeguarding the position of vulnerable patients and ensuring their rights are upheld is personal contact between the patient and someone whose job it is to explain the position from the patient's point of view..."

Two years later Advocacy Alliance was born, sponsored by The Spastics Society, MIND, MENCAP, One-to-One and the Leonard Cheshire Foundation.

It is a registered charity, with a full-time co-ordinator, and an administrator and recruitment officer who are both part-time.

Government blessing was immediate: Advocacy Alliance won second place in the 1981 awards for the International Year of Disabled People. Now it is funded by its founders, the DHSS, the King's Fund and the Mental Health Foundation.

The end of this year sees the completion of the Alliance's first phase: to establish advocates in three hospitals. Groups now exist at Normansfield, Teddington, Middx, and at St Ebba's, Epsom, Surrey. The first training course has just been completed at St Lawrence's, Caterham, Surrey.

There is no shortage of would-

be advocates, but they have to be carefully selected and trained.

Good working relations with hospital staff and administrators is essential, so project teams composed of members of the Alliance's board and the hospital meet regularly to monitor a project and advise on problems. In addition, each advocate support group meets monthly.

Hospital staff have been most co-operative. They have organised events for advocates and their matched residents, and invited advocates to go on holidays. Advocates may attend the part of a hospital meeting which is concerned with assessing their resident.

From their side, advocates have been able to raise successfully various issues on behalf of their residents, such as clothing, money, compensation for damage to property.

The Alliance is now planning six more projects.

There's a breath of fresh air blowing in the mental handicap services. It's a beginning.

John Tizard

John Tizard is Research and Development Officer for The Society's Social Services Division and also Vice-Chairperson of Advocacy Alliance.

For further information contact Sally Carr, Co-ordinator, Advocacy Alliance, 115 Golden Lane, London EC1, Tel: 01-253 2056.



Focus 4 Studios



The winners and judges. Standing, from left to right: Tim Yeo, Sara Jones, Mrs. Joyce Smith, Colin Cullimore CBE, Dafydd Wigley MP and Jason Fowler. Sitting, from left to right: Karen Tilford, Calum Morrison, Mark Hodgins, Denise Macdonald, Joanne Doyle, David Cook, James Savage, Jane Evans and Jenny Price.

## Their achievement, our challenge

**1st: David Cook, 14**, from Stafford. Congenital heart disease. "David has spent so much time in hospital, yet he is always positive and has packed more into his life than many able-bodied children," commented Sara Jones, one of the judges.

His grandmother writes of David, "He does all the things he shouldn't do: stays up late, goes to the fair, and tries everything out... His efforts to walk and to lead as full a life as possible, in spite of past and present drawbacks is taking great courage and determination. He is a little giant."

**2nd: James Savage, 11**, from Cirencester. Wernig-Hoffman disease. In spite of his severe handicap James attends a normal secondary school, where with the help of a Welfare Assistant, he is fully integrated into the life of the school.

"On the first day no one knew for sure whether I was safe to talk to. On the second day, a few talked to me and then their friends too. Now it is fine," said James.

In the citation, James' headmaster writes, "He has been accepted without any sentimental or emotional overtones. Through contact with James, the bully, the brash, the boisterous, the selfish has each become less so. The timid, withdrawn and less able have often emerged from their shells and succeeded beyond their expectation, and all this because of the happy boy in the wheelchair in their midst."

**3rd: Mark Hodgins, 14**, from St Leonards. Cerebral Palsy, no speech. Mark has mastered his Bliss Board and works hard to achieve tasks that seem impossible at the start, like feeding and dressing himself. He attends Scouts, and a camera club, has mastered the workings of a computer and uses his wheelchair to good effect when defending in hockey and skittleball.

**3rd: Denise Macdonald, 16**, of Exmouth. Stills disease, blind, wheelchair bound. Denise studies by braille, using an electric Perkins brailer and an electric typewriter. Last summer she gained 7 "O" levels and is now studying for "A" levels. She hopes to go on to University and eventually to have a career with computers.

Her paediatrician wrote of her: "Denise is a truly remarkable character, distinguished by her great courage and her high intelligence, despite her blindness and the severity of her rheumatoid arthritis."

### The other finalists

**Joanne Doyle, 8**, of Wednesfield. Deformed spine. In spite of painful operations on her back, Joanne is always cheerful and rejects any special treatment in school. Her headmistress writes, "I have never seen that child other than smiling - even joyful - unassuming and co-operative. Her courage is beyond praise."

**Jane Evans, 9**, of West Boldon. Stills disease, wheelchair bound. Jane is a Guide and attends a nor-

next operation and how much height he will gain."

**Jenny Price, 6**, from Bloxwich. Paraplegic, epilepsy, scoliosis. Jenny's mother writes, "At school she gets excellent reports and even got a bronze endeavour award for swimming in the hydro pool at school. She is now trying for her silver swimming award and is learning to ride a specially adapted bike. What has pleased her most of all was joining the local Brownies."

It gives me so much pride to see my daughter Jenny do things



Dafydd Wigley MP congratulates second-prize winner James Savage. Each finalist received an inscribed medal. The first prize-winner also won £200 and a silver cup; the second won £75, and the third £50.

mal school where she has lots of friends. She always wants to be treated like the other children and refuses any fuss or extra attention.

**Jason Fowler, 13**, from London. Blindness and Cerebral Palsy. Jason's headmaster writes, "Jason has not only conquered his blindness to the extent of coming to this (Grammar) school and making a start on courses which will lead to "O" and "A" levels, but also takes a full part in all outdoor activities, including sport, games and swimming, and is a member of a local Scout group."

**Calum Morrison, 9**, from Argyll. Hydrocephalus and hereditary dwarfism. "Calum has had several operations to lengthen his legs, followed by long periods in plaster," writes his teacher. "Throughout the trauma he has shown great courage and determination and has never lost his sense of humour. He is already talking about his

that need such a struggle and so much effort, and to see her determination to lead as normal a life as possible."

**Karen Tilford, 12**, from Redhill. Paraplegic. Karen attends a normal comprehensive school. "I'm treated just like everyone else - I get told off just as they do," Karen said. "I can't do games, but I help with a remedial class instead. I want to be a teacher."

Karen is a patrol leader at Guides, and last summer went on an adventure holiday with her school. She tackled canoeing, archery, rock climbing and shooting.

**Paula O'Flaherty, 10**, from Ipswich. Brittle bones. Paula is an enthusiast in everything and a great inspiration, full of fun and participating in all activities, says her teacher. "Perhaps her greatest achievement is that she has overcome her fear of fracturing to the extent that she never allows her handicap to prevent her from doing what she wants."



Runners stretched back as far as the eye could see as over 3,000 athletes took part in the Windsor Great Park Half Marathon. 7,000 spectators watched the race.

## The sponsorship

Over 3,000 athletes took part in the Windsor Great Park Half Marathon held in October and organized by Alysia Hunt, Senior Appeals Officer for Berkshire. The marathon has already raised more than £19,000 gross for The Society, and so far only about 12 per cent of the runners have handed their money in, so the total will soar higher.

About 7,000 spectators watched the race, which took place on private land - the Queen's back garden.

The winner was 21-year-old David Powder from Enfield, Middlesex. He ran the 13.1 mile route in 1 hour, 10 minutes and 20 seconds.

Hugh Slater, of West Molesey, Surrey, ran the race in his wheelchair, manoeuvring himself backwards up the hills. He finished the race in spite of a puncture, and won a special prize for determination.

October was a busy month for Alysia Hunt. She also organized a sponsored aerobic display at White Waltham, Maidenhead.

Twenty-three people took a turn at sitting in the open front cockpit of a small plane, while the pilot behind them looped the loop, flew upside down, and did other aerobatic stunts.

The twenty-three adventurers raised £2,300 between them, and Hilary Bartlett raised £1,000 by herself. Participants ranged from a 16-year-old, to 56-year-

old John Coombes, chairman of the East Region, who commented he hadn't done anything like it since the last war.



Hugh Slater, who set off in the rain one and a half hours before everyone else, reaches the finishing line.

The Princess Marina Centre at Seer Green, Buckinghamshire, has been involved with many sponsored events this autumn. In October, 13 residents from the centre took part in a sponsored wheelchair mini marathon to raise money for the spinal injury unit at Stoke Manderville Hospital. Everyone was in fancy dress.

The course was approximately 14 miles, starting and finishing at The Crown Inn, Bray.

The mini marathon was a great success and raised more than £17,000 for the unit.

Also in October, the Princess



A team of cadets from Chesbam, Buckinghamshire, get in some target practice on the assault course at The Princess Marina Centre.



Windsor Observer

# Parties and Prizes for SOS

A gala evening held by Selfridges in September has raised £5,000 for the Stars Organization for Spastics.

Some 350 guests each paid £10 to attend the champagne reception and fashion show, at which a full range of Selfridge's autumn clothes were modelled.

Serena Sinclair of the *Daily Telegraph* compered the show, which was attended by among others Lady Anne Tennant, the Countess of Westmoreland and designer Roland Klein.

Guests signed their names on £5 notes to take part in the raffle, and the winning note was drawn by actress Susan Hampshire. The prize was £2,000 in Selfridges gift vouchers, to be spent on the fashion floors.

Roy Stephens, Managing Director of Selfridges, later presented Sheila Rawstorne, Administrator of the SOS, with a cheque for £5,000 from the proceeds of this successful evening.



Richard Young

(Above) The top table at the SOS annual ball held at the Hilton on 15 November. From the front, moving clockwise: Sir Frederick Pontin, Mrs. Jarvis Astaire, Charles Harding, Mrs. Michael Samuelson, The Earl of Arran, Lady Glenconner President of SOS, Jarvis Astaire, Mrs. Tim Rice, Chris Nelson, The Countess of Arran, Tim Rice chairman of SOS, guest of Sir Frederick Pontin, Michael Samuelson and Mrs. Chris Nelson.



(Right) HRH The Duchess of Kent, patron of The Society, chats with Mr. and Mrs. Jack Howarth at the SOS Eden Vale Gala Dinner on 1 November.

## SOS National Raffle Results

1 182540	2 166624	3 294284
4 226012	5 309280	6 021540
7 195043	8 132724	9 036726
10 047781	11 181900	12 162477
13 003583	14 244780	15 235747
16 225481	17 121596	18 229192
19 030041	20 062435	21 263095
22 017714	23 231049	24 165769
25 052000	26 002362	27 052451
28 245220	29 036144	30 038432
31 178649	32 098779	33 071424
34 035755	35 274721	36 129221
37 067700		

over the starting line at the Windsor

## game

Marina Centre held a sponsored assault course and open afternoon. Teams of young people from local schools and clubs tackled the assault course. They were raising money to renew the building which houses the centre's hydrotherapy pool.

"The day was very successful as a social event and as an exercise in integration," said the Deputy Warden, Rosanne Wynyard-Wright.

The Society is £2,000 better off since a sponsored mass break-out from Manchester's Strangeways Prison organized by the North-West Region on 12 November.

Six teams of three "escaped" from the prison wearing prisoners' costumes and weighted with balls and chains. Each team aimed to get as far away from Manchester as possible using initiative, but no money.

One team had a hair-raising journey to the airport in a rally car. It covered ten miles in ten minutes and left the car smoking on the runway, then flew by private plane to the Shetlands.

Another team, consisting of policemen and a radio producer, took the London shuttle from Manchester airport and then hitched down to Southampton.

Teams travelled as far as Alicante in Spain, Calais and Dublin. One took things more slowly and pushed each other the 40 miles to Buxton in a shopping trolley. As they struggled up hills, people who had heard of their progress on the radio came out and encouraged them with donations for The Society.

Prizes will be awarded in Stangeways Prison officers' club to the team which travelled furthest, the team which travelled furthest by land and sea, the one travelling furthest in the British Isles, and the one travelling furthest by human effort. There are two other prizes: one for the team which raised the most money, and the other for the team which used the most ingenuity in planning its escape. No one's the loser!



The "convicts" make their break-out from Strangeways Prison.



Block 13 team push on to Brixton after making its escape.

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# "People still expect to be wet, smelly and uncomfortable. We need to raise their expectations."

Mary Wilkinson finds that incontinence is neither inevitable nor unmanageable

Incontinence is big business. More than 87 companies produce equipment, according to a report prepared earlier this year by The Royal College of Nursing and Squibb Surgicare. It is estimated that the National Health Service spends £36 million a year on incontinence equipment (£24 million of that on pads and pants).

Yet there are no consumer guides and barely any research has been done to help the patient, the prescriber or the Supplies Officer to avoid poor quality goods or inappropriate aids. Local health authority services vary considerably from one area to another depending on the knowledge and interest of the professionals.

The trouble is that incontinence is not only unglamorous; it is frequently considered inevitable, especially among the elderly. Consequently it has attracted little medical attention and the nursing profession is left to mop up. Yet incontinence is a symptom, and once its cause has been established various forms of help are possible.

The apathy stems from ignorance. Doctors and nurses lack training in the diagnosis and treatment of incontinence. A report was published last month by the working party of the Incontinence Action Group, chaired by Professor John Brocklehurst of Manchester University. It found that the average time spent on urinary incontinence in medical schools was 71 minutes, and that no textbook on the management of incontinence was available for nurses.

So on one side we have the district nurse with a bundle of all-purpose pads under her arm and on the other the doctor whose limited understanding of the problem may lead him to overlook a simple cause.

Dorothy Mandelstam is Incontinence Advisor at the Disabled Living Foundation and Chairman of the Association of Continence Advisors. She tells of how an old lady of 94 became incontinent after she had come into hospital for a minor operation. Thinking exclusively in medical terms, the consultant sent her for a gynaecological examination. Only when Dorothy Mandelstam talked to her did the truth emerge: in this new environment, she couldn't reach



Changing peoples' attitudes is one of the hardest things to do.

the lavatory without assistance and help was never there when it was needed.

"People don't think of everyday problems as a cause", commented Mrs Mandelstam. "Always look at the simple, obvious things," she advises.

Once you have discovered the cause of incontinence, it is possible, she believes, to find remedies or to make improvements in management.

Environment can play an important part, and it is comparatively easy to provide a urinal beside the bed, make sure lavatories are recognisable and accessible, and that clothing is manageable.

On the other hand, inadequate diagnosis can make unnecessary work and trouble. Overflow incontinence of the bladder and bowel are commonly found among elderly and disabled people in residential centres. They are often caused by severe constipation and bring many people into hospital unnecessarily. "If we improved the management of bowels", says Dorothy Mandelstam, "we would cut down on an enormous amount of incontinence."

Some forms of incontinence,

which are more intractable, can with proper assessment and a positive approach be greatly improved. Where a mentally handicapped child or adult has reflex incontinence (the full bladder empties without awareness) a parent can establish a pattern of rigid toileting. But if the patient is aware of wanting to pass urine, a chart can help reveal the natural pattern of the bladder so that toileting can be arranged accordingly. This is much more likely to be successful than the old-style routine toileting at specific times.

Slowly the views of Mrs Mandelstam and other pioneers are getting across. In 1981 the Association of Continence Advisors was formed. Now it has nearly 250 members drawn from various disciplines and manufacturers, who want to promote continence and the management of incontinence through discussion, education, research and the development of aids. It has published a *Directory of Aids*, the first comprehensive list.

In 1976 the Department of Health recommended that there should be full time incontinence nurse advisors in every health district. So far there are 38, some

of them in special units.

Incontinence clinics have been established in some major cities where patients can receive co-ordinated advice, assessment and treatment.

Multi-disciplinary training is now taken more seriously: the Middlesex Hospital is one example of a hospital where nursing, medical, social work and physiotherapy students share courses on continence.

Research into incontinence equipment is also developing. Sponsored by the DHSS, the Incontinence Clinic at St Pancras Hospital, London, has recently tested eight popular incontinence garments among 113 consumers in the community and in Part III accommodation. Not only did it find, predictably, that plastic pants are usually unsuitable, but also that people's requirements vary, and cannot be met by providing a limited range of products for all circumstances.

"It has become clear," says the report, "that the needs of those living in Part III accommodation are very different from those living in the community. These people should therefore be assessed as a separate group."

Absorption capacities quoted by manufacturers were found to be misleading. The report called for "standardised functional specifications" to use in describing garments and individual requirements. Preparing such specifications for the DHSS will be the next project.

Dr James Malone-Lee, Clinical Lecturer in Geriatric Medicine at St Pancras, has just completed a research paper on the technology of incontinence garment manufacture which sheds light on three aspects of performance: absorbency, waterproofness and the effect on the skin. Some new absorbent materials, he says, offer "a great hope for people". He is planning further research.

All this is heartening to consumers and to those who care for them. But there is still a long way to go.

"People still expect to be wet and smelly and uncomfortable", says Christine Norton, Secretary of the Association of Continence Advisors. "We need to raise their expectations and get them complaining about what is not available — to manufacturers and to the NHS. Why, for example, should men be able to get equipment from the NHS but women have to rely on the uneven services provided by local health authorities?"

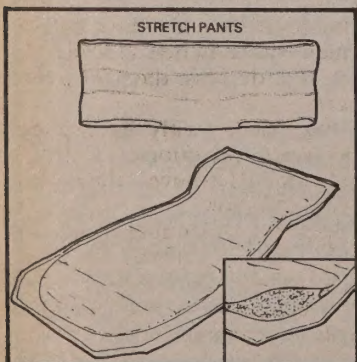
As Dorothy Mandelstam says, "It's a constant struggle."

*The Incontinence Advisory Service at the Disabled Living Foundation, 346 Kensington High Street, London W14 8NS, tel: 01-602 2491, provides advice, literature — including practical notes on management — and training seminars for professionals.*

*The Association of Continence Advisors, C/o The Disabled Living Foundation, is a multi-disciplinary organisation for professionals.*

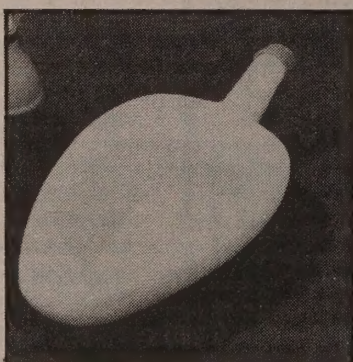
*A Community Study of the Performance of Incontinence Garments is available, free, from the DHSS Store, Health Publications Unit, No 2 Site, Manchester Road, Heywood, Lancs OL10 2PZ.*

*Action on Incontinence, report of a working group of the Incontinence Action Group (KF Project Paper No. 43), is published by the King's Fund Centre, 126 Albert Street, London NW1 7NF, price £1.50.*



All the pads and pants shown here performed well in the St Pancras Community Study. Molnlycke's T-Form Diaper (top left) was thought particularly suitable for Part III homes; the Lycra stretch pants wore better in the community.

Smith & Nephew's Dandeliner pad (lower left) was more popular with people who were mildly incontinent. Dandepants (not shown) are considered an improvement on the

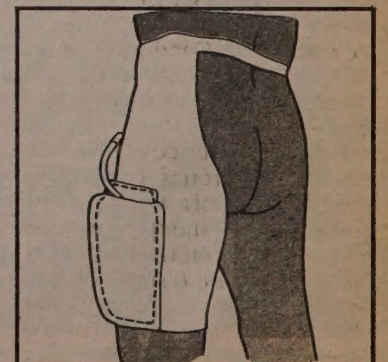
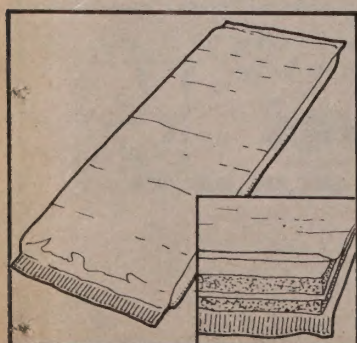
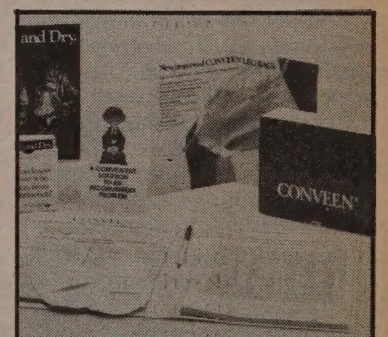


stretch pants. Kanga Lady pants (left) worn with a single pad were very popular in the community. The Standard Kangapant (not shown) has a front opening version for disabled people. The Suba-Seal urinal (above) is light, non-spill and can be used by the patient herself. "Edgware" trousers (right) have a high cut back and long fly. Special braces allow them to be dropped and pulled up with one

hand. Contact the Disabled Living Foundation.

Coloplast products (right) include a leak-proof Conven Drip Collector, invisible under clothes, and the Conven Male Incontinence System, an external sheath with flexible seal, attached to a leg bag.

The Netti Urine Bag Holder (below right) comes as a comfortable one-legged, stretch pant. From Brevet Hospital Products.





## OUTLOOK

### Arts

#### Graeae in "Not Much to Ask"

Graeae's first commissioned play, *Not Much to Ask*, was adapted from Charlotte Bronte's *Villette* and draws on the parallel between the life of its Victorian heroine Lucy Snowe and the similar isolation and frustration experienced by people with disabilities today. Thus the narrative shifts between centuries and the characters drop their roles to make their contemporary statement.

To a certain extent this is effective. I, for one, sat up as Richard Gilling confronted the audience to make it clear that an inability to be understood, (whether because Lucy meets foreigners without a command of English or because of his own disability) bears no relation to intelligence.

However, I felt that the structure of the play, retaining much of the novel's long plot in a series of episodes punctuated by modern interludes with loud music and flashing lights, could not support so much.

Perhaps the flaw lay in attempting to adapt the entire novel rather than simply developing the idea that through the character of a plain Victorian teacher much can be said about modern attitudes to disability.

Even so, I enjoyed the evening and in particular the performance of Yvonne Poulson as Lucy and Richard Gilling as Monsieur Paul.

The music worked well too; at times suggesting the mannered restrictions of Victorian society and then changing mood to evoke the monotonous frustration of a contemporary day care centre.

Gill Parker

### Books

#### Conductive Education for Adult Hemiplegia

by Ester Cotton and Rowena Kinsman  
(Churchill Livingstone, 1983, £3.95, available from The Society's Bookshop, 12 Park Crescent, W1N 4EQ)

Conductive Education, introduced 15 years ago by Ester Cotton and The Spastics Society, has slowly developed all over the world and is now used in some twenty schools and units in the UK. It started among children with cerebral palsy and only over the last few years has it been applied to adults and people with acquired handicaps such as strokes, Parkinson's Disease and accidents.

The book describes Conductive Education and its background. The system is innovative and controversial because it crosses professional boundaries by creating a Conductor and a daily routine which drastically changes the patient's day and the staff's duties.

One chapter describes the structure of groups and emphasizes the value of a well-balanced group where the patient gets support and motivation from other members. A small section describes how Conductive Education can help aphasic patients.

Close and precise observation

of the patients is essential, and one chapter provides a detailed chart with guidelines for assessment.

Another deals with different ways of making the tasks easier for patients. Success is the force in Conductive Education and Rhythmical Intention - how speech is linked to movement - is the main technique. It is described in some detail, but I was disappointed that no reference was made to the vast body of supportive research available. Speech can capture attention, which makes it possible for even very young children to work for a remarkably long period without failing concentration.

The authors have developed a shorthand code which, once mastered, should save a lot of time in the writing of programmes.

The book ends with a series of tasks followed by suggestions for functional tasks e.g. how a hand programme teaches the skills necessary for drinking or slicing bread.

This book is an excellent manual for anyone interested in the teaching of learning and the teaching of function. We have waited some time for such a book and look forward to future volumes on mother and baby units.

Lillemor Jernqvist

#### Outdoor Activities for Handicapped people

by Mike Cotton  
(Souvenir Press, Human Horizon Series, £7.95 hardback, £5.95 paperback)

*Outdoor Activities for Handicapped People* has been written as a companion volume to the author's earlier book, *Out of Doors with Handicapped People*. Much of the author's experience has been gained during the 8 years he spent as Warden of The Society's Churchtown Farm Field Studies Centre. In addition, he has called upon the experience of many of the staff at Churchtown Farm as well as informed people from outside organizations.

The book introduces disabled people to the opportunities in a number of controlled risk activities, some of which might daunt many able bodied people. There are chapters on swimming, sailing, canoeing, fishing, riding, rambling, climbing and winter sports. There are some excellent photographs, a useful bibliography and a basic list of contact addresses.

The importance of safety both for the instructor and instructed is stressed in all these activities. With this in mind, it must be emphasised that the book is an introduction, albeit a useful and readable one, and not an instruction or safety manual.

Guidance on how to teach a particular activity should be obtained from the governing body of that activity or from one of its qualified instructors who has experience of teaching the disabled. To date, no disabled people have been seriously hurt in outdoor pursuits, but if there was to be such an accident, the resulting publicity could considerably reduce the available opportunities.

It is to be hoped that this book will be read widely and acted on by professionals, by parents and by the disabled themselves. Many are already converted and much is happening, but all should have the right to know and make use of the opportunities that exist.

Stephen Williams

### Fashion

#### New ideas for disabled people

A seminar in London last month brought together individuals and organizations involved in designing and producing fashionable clothes for disabled people. Little has yet been done to make functional but attractive clothes for the disabled, and those who are involved recognize a huge unmet need and a potential market.

Nellie Thornton is Project Director of Fashion Services for the Disabled in West Yorkshire. She supplies a unique service including a training centre where disabled students come for week and day courses to design and make their own clothes.

"They learn about line, colour, how to camouflage physical faults and draw the eye away from the disability towards the best feature," Nellie Thornton explained.

Each student designs his or her personal basic pattern and then makes a toile - a calico model of the pattern, made to fit exactly. The toile can be used to make any other garment and guarantees a good fit.

"It gives the girls great pleasure and a lot of confidence to make and design their own clothes," she said.

Community care workers also come to the workshop to learn about the clothing needs of the disabled.

The centre will design and make clothes to order for disabled people all over the country. As the service is funded by the Urban Programme and the Manpower Services Commission, it can provide bespoke garments at off-the-peg prices.

Research also goes on into new fabrics, testing them for warmth and wear.

"I believe local authorities must do something like this in other areas," said Nellie Thornton. "It has to be regionally operated so you can get to the person who is wanting help."

Fashion for the disabled would seem to be a matter for the individual rather than mass market. "You have to sit down and work out each person's problem," said Nellie Thornton.

But for certain specialized products there may be a mass market. Alan Myers' company Artimaze, manufactures mix and match leisurewear. In conjunction with Fashion Services for the Disabled, Artimaze has recently designed a new range of clothing with special features for the disabled.

So far, three designs are on the market: track suit pants and two alternative track suit tops. Each



Three designs marketed with the disabled in mind by Artimaze. The suits are now available at an introductory offer of £24.95 from Artimaze Ltd., 118 Wood Lane, London, NW9 7LX. The garments have Velcro cuffs, pockets above the knees and diagonal zips.

alternative track suit tops. Each is made of stretch acrylic/cotton fabric for warmth and easy washing and comes in three colours and eight sizes. The wrist and ankle cuffs open wide with Velcro studs: the pants are cut high at the back to prevent gaping, have pockets just above the knees and an elasticated waist. The tops have zipped necks for

easy access.

If these designs prove commercially viable, Alan Myers hopes to bring out others in the Spring. They will include a jacket with removable sleeves, a tabard, and a wrap over skirt with hidden culottes which can be easily undone. All the designs will be made of the same stretch fabric and will mix and match.

"I've taken the concept of normal leisure wear and just adapted it. I've tried to create a fashion image," he explained.

Artimaze now faces the problem of reaching disabled people. "The marketing has to be done through organizations, and I'm not sure if they go beyond the professionals to the person in a wheelchair," he said.

Another company producing special clothing for the disabled is Dri-Rider Limited. Its designs come from fashion students working under the direction of Lindsay Robertson at Bristol Polytechnic.

The students learned to appreciate the design needs of the disabled by sitting in wheelchairs and drawing each other. As they designed, they made constant reference to the wheelchair.

Dri-Rider's original brief to the students was for a weather-proof garment for the wheelchair-bound - the result of which was launched at NAIDEX. But the designs did not stop there.

"We had a vastly interesting and varied collection of clothes," said Nick Matthews, the company's director.

Now he is planning to advertise in various journals and then to introduce more examples of the students' work possibly via a mail order catalogue.

"I have looked at what's going on in the U.S. and in Scandinavia," he said. "Some people there seem to think marketing clothes for the disabled is commercially viable. I'm hoping things will pick up here."

Theresa Allen

Nellie Thornton, Fashion Services for the Disabled, B270-B320 Saltire Workshops, Ashley Lane, Shipley BD17 7SR, Dri-Rider Limited, The Yews, Mark, Highbridge, Somerset TA9 4QE.



The Dri-Rider suit is made from a water and wind proof fabric which is water permeable to reduce condensation. The separate cape and lower body cover have concealed side zips which can be operated from both inside and outside the garments. The shoulder is fastened with Velcro and there are two types of headwear available. Both cape and leg and lower body cover have a detachable warm fleecy liner. The suit comes in a range of colours.



Mothers learn to design clothes for their disabled children at a course run by Fashion Services for the Disabled.



# Share Your Problems

With Margaret Morgan

## Where does he go from here?

"Our son will be leaving a residential special school next summer. We are really quite worried about his future and no one has been able to give us much idea about what he is going to do in the future, and how we are going to manage. Matthew is severely handicapped and he needs a lot of help. He will miss the organised life and his friends at school. Holidays have been a constant headache. Whatever are we going to do when he is at home for good?" Planning Matthew's future is obviously very important to you and to him and I am rather surprised that no one has talked over possibilities with you yet.

You don't say how old Matthew is, but if he is still under 18 when he is due to leave school, he should be able to continue his education for another year or two either at a residential special college or at a local further educational establishment.

If the Specialist Careers Officer who visits Matthew's school has not already been in touch with you, you should contact your local Careers Office and ask for an appointment. The Spastics Society also has several Careers Advisory Officers and if you get in touch with the Family Services and Assessment Centre, 16 Fitzroy Square, London W1P 5HQ, they will put you in touch with the Careers Advisory Officer for your area.

Unfortunately the facilities for severely handicapped young people are rather unsatisfactory in some areas. Social services departments have a responsibility

under the 1970 Chronically Sick and Disabled Persons Act to provide recreational and other services, but very often these are geared to the needs of people with mental handicaps or very elderly people.

I think you would be wise to find out whether local voluntary organisations run work or day centres that might be suitable for Matthew. The local spastics group may be able to help too.

## Why has my allowance been cut?

"I can't understand why the Attendance Allowance which I have been receiving for my severely handicapped son for a long time has been reduced to the lower rate. John is now 16 and he isn't any less handicapped now than when he received the higher amount."

There does seem to be a problem here and I think that you should ask for a review of your son's situation. To do this you will need to write to the Attendance Allowance Board and this should be done within three months of the decision to reduce the amount. You will be well advised to explain in as much detail as possible about John's special needs and what you have to do for him, particularly at night. Supporting letters from your doctor and social worker will be helpful too.

If it is more than three months since the decision was made, you should write to the Attendance Allowance Unit at the DHSS, North Fylde Central Office, Norcross, Blackpool FY5 3TA, explaining the position and asking their advice. Be sure to quote all the numbers on your



Nigel Tuckett

forms, so that they can trace John's application quickly. I do hope that this problem can be sorted out satisfactorily.

## A pet of my own

"Why can't I have my own dog in my room? The staff of the centre say that pets aren't allowed, but the Warden has a large retriever which is always in our sitting room. It doesn't seem fair, does it? I would love a pet of my own."

I agree, it does seem hard that staff can keep a dog while you can't, but I expect there are good reasons for this rule. I am sure there would be problems if all the residents decided that they wanted their own dogs. I wonder who would take the responsibility for exercising, feeding and house-training them?

Have you ever thought of having a budgerigar? I expect this would be allowed and a budgie can be very good company. Caring for a bird in a cage isn't difficult and a budgie certainly would not need to be taken out for a walk each day!

Dogs can be expensive to feed and they are really quite a responsibility. So I should just enjoy your Warden's retriever and let the Warden look after him!

Why not have a word with the staff about keeping a budgie?

Happy Christmas everyone!

# What's On

## Courses at Castle Priory College

**Paget Gorman Sign System** – an introductory course for teachers, therapists, parents and care staff. 4-8 January. Tuition £50, residence £70.

**Child Abuse and Neglect** – aimed at bringing together various professionals from social work, the law, medicine and education. 11-13 January. Details of fees available on request.

**Autistic Tendencies in Children With Minor Physical Disabilities.** Run in conjunction with The National Autistic Society. Tuition £36, residence fee £35.

**Derbyshire Language Scheme** – a teaching workshop. Places strictly limited. Tuition £54 (materials not included), residence £52.50.

**Staffed Houses for Severely Mentally Handicapped People** – course on use of ordinary housing to meet residential needs of mentally handicapped people who require considerable staff help. 27-29 January. Tuition £36, residence £35.

For more information about any of these courses write to Castle Priory College, Thames Street, Wallingford, Oxon, OX10 0HE. Tel: 0491 37551.

## Exhibition

**Young Blood** is an exhibition of the work of young designers from 60 art and design colleges in Britain. The exhibition, which will run from 23 November to 15 January at the Barbican Art Gallery, London, will present a selection of new ideas in fashion, furniture, domestic industrial products and aids for the handicapped. Young Blood will be open between 10a.m. and 7p.m. Tuesday to Saturday, and noon to 6p.m. Sunday.

## CLASSIFIED

**BRAUNE BATTERY CHAIR** for sale. All weather hood, detachable side lights, direction indicators, battery charger and spare wheel. 1980 model, in very good condition. £800. Tel: Barnsley 754872.

**VESSA VITESSE POWER CHAIR** for sale. Left side control, kerb climber, 16 inch seat width. Recently serviced, good condition. £700 o.n.o. Tel: 01-767 4626, ext. 27, Alison or Beverley.

**GAY C. P. GENTLEMAN** aged 44 would like to hear from someone in similar circumstances. He has good mobility and his interests include the theatre, classical music and travelling. Contact Michael Peskett, 29 Hurstlyn Road, Liverpool, L18 9TX.

**WHEELCHAIR WANTED** by hotel catering for handicapped children. Manual or electric chair would be gratefully received. Suitable for child and/or adult. (Adults use the hotel off-season). Contact: The Manager, Collwall Court, Pages Avenue, Bexhill on Sea, Sussex. Tel: 0424 211491.

## OBITUARIES

### "Burry"

"Burry" has gone. It is sad news. He died in November. As he would have said in his jocular way, "There aren't many of the old ones left, and now there's one less!"

Ernest Burrington ("Burry" to his many friends) served the cause of cerebral palsy very well.

He was one of that intrepid band of founder Executive members in 1952. And the first man to go on radio in Britain to tell the public about "Spastics". And the first man to show us how to run a real razz-a-ma-tazz appeal. It processed round Bristol, bands playing, pretty girls on floats, the lot, and raised £1,200 in one day (£7,000 in 1983 values.) It just about saved the baby Society from bankruptcy.

"Burry" was a tall, handsome, slow-speaking Somerset man, a first class salesman of big computing systems – National Cash Register and Remington Rand. His drive, enthusiasm, business sense and appreciation of risk taking was invaluable to an Executive Committee lacking in business minds.

When he moved from Bristol to Welwyn Garden City he became involved closely with Sherrards, the Society's Employment Training Centre.

He leaves a son, Robbie, who was a pupil of St Margaret's and Thomas Delarue, and then an employee of ICI.

Ian Dawson-Shepherd

### George Robinson

The death occurred on 2 November of George Robinson, after a long illness. He was a founder member of Wolverhampton and District Spastics Society and Chairman from 1970 until his resignation in October because of ill health. He then became President of the society.

Throughout many years of devoted service, George never lost his enthusiasm, and worked unceasingly for all cerebral palsied people in the area. He was actively supported by his wife.

George was a friend to everyone in the society and will be greatly missed. He will be remembered with affection and gratitude for all he did.

Monica Allen

## ANNOUNCEMENTS

**Special offer. With a Little Help** by Philippa Harpin, (Muscular Dystrophy Group 1981) is a guide to aids and adaptations for people with muscular dystrophy and allied neuro-muscular diseases. There are eight spiral bound volumes giving information and numerous diagrams about adaptations, bedroom clothing, bathrooms, household and seating, communication, mobility and leisure. Useful for families, therapists and teachers. Normally £7.95, the set is on offer to *Spastics News* readers for £2.50. Cheques should be made payable to The Spastics Society, and sent to Liz Proctor, The Spastics Society, 16 Fitzroy Square, London W1N 4EQ.

The National Bus Company has produced a new leaflet called *Your Next Move*, which describes 15 specially converted

buses and coaches that are available for hire by disabled people. The leaflet was produced by the NBC's Advisory Group on Disability. All the vehicles described have been converted under stringent safety guidelines. The area in which each vehicle is available for hire is listed together with a brief description of the vehicle and details of hire arrangements. Copies of the leaflet can be obtained from the Public Affairs Department, National Bus Company, 172 Buckingham Palace Road, London SW1W 9TN.

**Help Yourself to the Arts** is a survey of arts facilities for the disabled in the East Midlands. It contains detailed information about facilities at theatres, museums, concert halls and colleges in the area of Leicestershire, Nottinghamshire, Derbyshire (except the High Peaks), Northamptonshire and Milton Keynes. For a copy of the survey send a large SAE (17p) to: Annie Delin at East Midlands Arts, Mountfields House, Forest Road, Loughborough, Leics.

The Spastics Society Bookshop now has an up-dated list of its available publications. The list can be obtained from the bookshop, 12 Park Crescent, London, W1N 4EQ. Tel: 01-636 5020, ext. 241.

Gowrings Mobility International has come up with a useful idea for disabled motorists who need enough space around their vehicle to get a wheelchair in and out. The company has produced a bright yellow and red striped adhesive sticker to be affixed to the inside of a car window. The sticker says, "Don't park too close – I have to get my wheelchair in." The sticker is available for £1 including post and packing from Gowrings Mobility International, The Grange, Lower Way, Thatcham, Newbury, Berkshire RG13 4PH.

"Tell me what you want and I'll get it for you", is a new report published by the Disablement Income Group Charitable Trust. It shows how disabled people usually pay, on average, 15 per cent more than able-bodied people for a normal week's shopping. The report is available from the Disablement Income Group, Atlee House, 28 Commercial Street, London E1 6LR, price £1 including post and packing.

The People's Dispensary For Sick Animals offers disabled people and senior citizens free veterinary treatment for their pets. The PDSA has 57 animal treatment centres round the country and also runs an auxiliary service operated through private vets in 20 small towns. For further information contact PDSA Head Office, Dorking. 0306-888291.

**Opportunities for the Disabled** is an employment agency for disabled people. Several new offices have been opened recently. Branches are at: 1 Bank Buildings, Princes Street, London EC2R 8EU, Tel: 01-726 4963; The Gate House, Wellhead Lane, Birmingham, B42 2SY, Tel: 021-331 4121; Woodstock Park, Sittingbourne, Kent, ME9 8AG, Tel: 0795 75652; The Business Advice Centre, 30 New Walk, Leicester, LE1 6TF, Tel: 0533 554464; PO Box 20, Hollingwood Avenue, Oldham, OL9 8EL. Another office will soon be opened in the Sussex/Surrey area.

**North-west Regional Committee** announces changes among its officers. The new Chairman is Joan Williams, 323 Withington Road, Chorlton-cum-Hardy, Manchester. She takes over from Dr. Millicent Regan who has retired. Mrs. Williams was previously Vice-Chairman and Acting Secretary of the Urmston and District Spastics Society. She is widowed and has one son and a cerebral palsied daughter.

Sharon Hughes is the new Vice-Chairman. She has recently been elected to the Executive Council, and has just obtained her M.Ed. in Special Education. Her special interests include education, and anti-discrimination legislation and consumer involvement. (She is Convenor of the new North West Consumer Group).

### WHEELCHAIRS

#### ASHLEY MOBILITY

Sole Distributors for Vessa Ltd's Range of Power and Hand-propelled, Wheelchairs in the Midlands, Powys, Avon and Somerset. Also Everest & Jennings Distributors and BEC and Batrac Agents. Distributors for the Elswick Envoy car for the disabled in the Midlands, Avon and Powys. All these makes are available on 'Motability' H.P., to recipients of the Mobility Allowance. Always a good selection of secondhand power chairs in stock. Write for details and coloured brochures. FREEPOST, Birmingham B25 8BR. Tel. 021-772 5364 or Ashley Mobility (Worcester), FREEPOST, Worcester, WR4 9BR. Tel. 28575 or Ashley Mobility, FREEPOST, Weston super Mare, Avon, BS23 3BR. Tel. 26011.





## Young Outlook

### Paint the Editor competition —the winners

Green eye shade? Cigar? The traditional image of a newspaper editor doesn't seem to fit *Spastics News* and none of the competitors thought so either.

You all had your own ideas of what the Editor looks like, and some of you came very close to the mark. Mary Wilkinson found her large glasses appearing on several pictures and also that harassed expression she gets towards the end of the month when the printing deadline approaches and there's still copy and pictures to be completed.

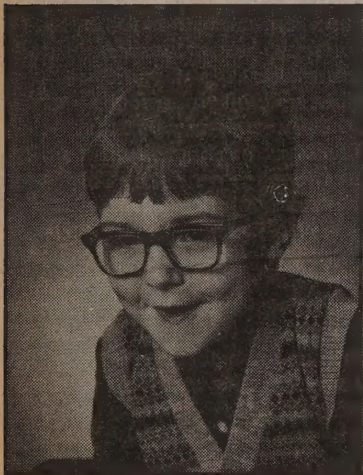
Judges Tim Yeo, the Director, Nigel Tuckett, The Society's graphic designer, and Mary Wilkinson were impressed by the range of styles and the time and trouble which had been given to some of the entries.

Their thanks go to everyone who made the effort to enter and to the parents and teachers who helped.

Also a special thank you to Winsor & Newton Reeves who generously donated two huge boxes of paints and crayons for each winner.



*This is what she really looks like!*



Noel Turner was the junior winner. His painting of the Editor with her glasses is above. The black and white photo cannot show his sense of colour.



Junior runner-up was Eleanor Kingsbury. See below for her painting. She captured Mary Wilkinson's glasses and dangly earrings very well.



*Choosing the winners.*

Winner of the senior section was **Lisa Chenery**, 14, from Dame Hannah Rogers School at Ivybridge, Devon. Lisa, who has athetoid cerebral palsy, paints with a brush fitted on to a head pointer. According to Ron Yiend, her teacher, she has a lot of artistic ability. "She really enjoys it," he says, "and she will work on her art right through the afternoon."

Runner up in the senior section was **Stuart Chudley**, 14, also a pupil at Dame Hannah Rogers School. Stuart is hemiplegic. He can use his hands for painting. "He has a lot of character, and enjoys many things at school — including art", says Ron Yiend. Winner of the junior section was **Noel Turner**, 7, from White Lodge Centre in Chertsey, Surrey. Though he is quadriplegic, Noel paints with his hands. Betty Wheatley, his teacher, describes him as an enthusiastic boy, keen to have a go at anything whether it is easy for him or not. How did he get the idea of the glasses? "Probably because he wears them himself," she said.

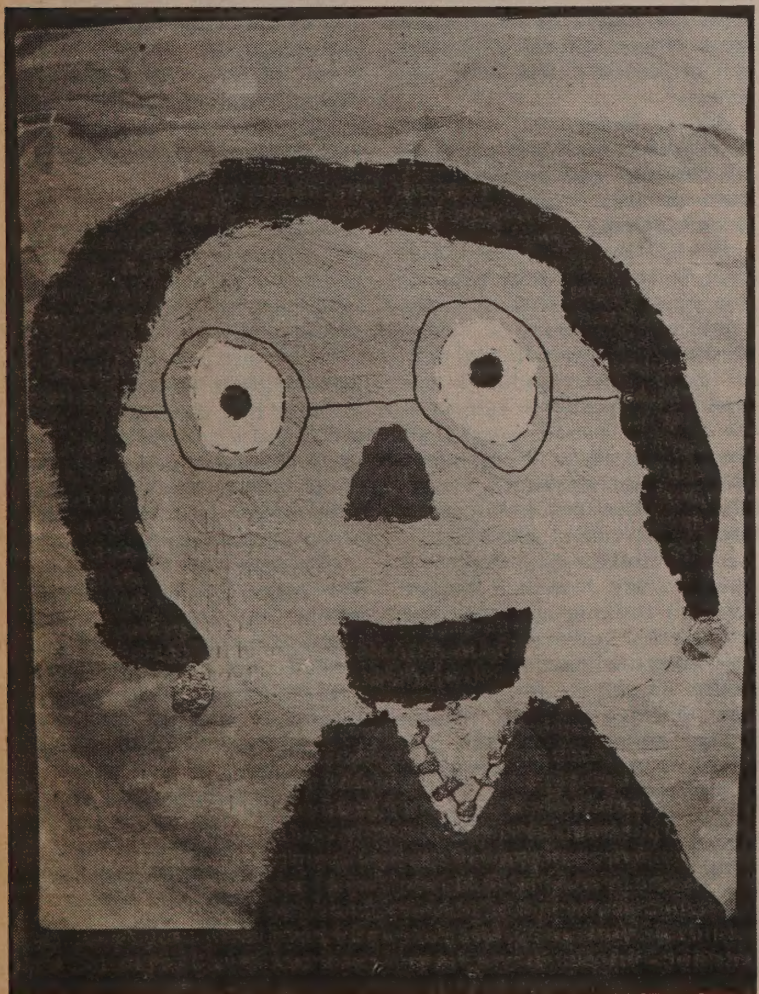
Runner-up in the junior section was **Eleanor Kingsbury**, 7, who lives at Caversham, Reading, and goes to Caversham Primary School. Eleanor is mildly hemiplegic. She likes going in for painting competitions. A picture she painted last summer for a school competition won her a pile of strawberries! "She's very persevering and always finishes anything she starts," says her mother, Angela.



*Lisa Chenery, winner of the senior section. Her painting is shown above. We liked the harassed expression.*



*Stuart Chudley, senior runner-up. See below for his painting. He has an individual style which appealed to the judges.*







Residents from 48 Boundary Road join staff to picket outside Camden Council Offices. The residents support NALGO's basic claim, but resent being used as a weapon between union and management.

## "Take us out of your battle"

Residents at 48 Boundary Road, a residential unit for 30 younger physically handicapped adults in London, are angry that they are being used as "battle fodder" in the struggle between management and NALGO residential care workers over pay and working hours.

"We believe that NALGO's claims are perfectly justified," said Rosemary Dawson-Shepherd, coordinator of the Boundary Road client group. "We agree with the aim, but not with the method of using the client group as a weapon."

NALGO is asking for payment for unsocial hours and overtime, parity of pay with other council care providers, and a nationally guaranteed 35-hour working week. The union is now balloting to work only office hours.

"If they vote yes, we will cease

to exist. Those who need night attention would have to go into hospital. All care would be reduced to the basic level. It is a very frightening situation, and it also makes us very angry. As people, we have a basic right to our care," Rosemary Dawson-Shepherd said.

In an attempt to support NALGO's aims with different methods, Boundary Road residents joined staff on 16 November to picket outside Camden Council Offices. Since then, they have issued a statement arguing their case to the media, NALGO and management.

"This is a straight battle between management and union — they must take it away from us. It's not as though we are steel or paper and you can leave us and go on strike at the end of a shift," she said.

## Linda finds a job

After having her story of job discrimination brought to the attention of the anti-discrimination conference in Immingham on 24 September, and from there to that of the press and public, one disabled Grimsby woman has found a job. She is 25-year-old Linda Petchey, who lost her leg in a motor-cycle accident 6 years ago.

Linda, who has 6 CSE passes, claims that late last year she was turned down for a job at a Grimsby Woolworth's store because she could not wear the uniform. She preferred to wear trousers because of her artificial leg.

"I had definitely got the job. The interviewer was saying things like, 'When you come to work on Monday...'. It was when she asked what size uniform I would need, and I explained about wearing trousers, that she cooled off and I didn't get the job", said Linda.

"I was really upset, but you get used to knocks and I didn't do anything about it. I only told friends and family until the conference".

As a result of seeing Linda's story in the *Grimsby Evening Telegraph*, a director at Grimsby veterinary chemists, Chapman and Frearson, interviewed her and offered her a job in the packaging department. Linda is enjoying her new work. "It's very busy, and everybody here is like one big family," she said.

Edna Coulbeck, wife of Ken Coulbeck of the Executive Committee, heard Linda's story at the conference. To her, it proves that discrimination is a reality.



Linda at work in her new job with Grimsby veterinary chemists, Chapman & Frearson.

"There wouldn't be a need for anti-discrimination conferences if people looked at things from the point of view of disabled people," she said.

But Audrey Laceby, Personnel Manager of the Woolworth's store in Victoria Street, Grimsby, says she has no memory of ever seeing Linda.

"I have no recollection of interviewing her and I have never given a job to anyone and then taken it from them. I was most surprised by all this and I think it is most unfair."

She says that though wearing uniform is part of the job, if someone had a reason for not doing so, that reason would be passed on to a higher authority.

"Woolworth's policy is that if a person can do the job we will employ them," she said.

Controversy apart, one thing is sure. "If Linda hadn't come to our anti-discrimination day", said Edna Coulbeck, "she wouldn't have got a job".

## Comments, please

Is there a case for a new national advisory body on the education of children and young people with special needs? The Department of Education and Science has recently set aside £10,460 for a working party to find out.

Before making its recommendations in March 1984, the working party has asked The Spastics Society and other concerned organizations for their comments.

The Society believes that there should be an advisory body and that it should be committed to a gradual move from separate education to a more community based comprehensive education system. This would involve the integration of all but a small minority, and would be in line with the requirements of the 1981 Education Act.

The Society also stresses that the proposed body should be independently funded.

"It couldn't be funded by Government," said Mark Vaughan, coordinator for The Society's Centre for Studies on Integration in Education. "It must be sufficiently independent to take a lead in the development of a new philosophy for meeting special education needs."

The advisory body should be concerned with the allocation of resources in education, the comment goes on. It should also recognize the educational needs of the 16-19 age group.

The Society recommends that guidelines should be laid down to change staff training and encourage recruitment of more teachers and ancillary staff to cope with increased integration.

If the advisory body is formed, it remains to be seen whether its priorities reflect those of The Society.

**STOP PRESS.** Government announcement on 1 December: from November 1984 a Severe Disablement Allowance will replace HNCIP and NCIP. Will married women gain at the expense of other disabled people? See *Spastics News* in January.

## Invasion!

The first Space Invader in The Society's industrial work centres has taken over Beaumont Products, Abbots Langley Works. Gone are the peaceful lunch breaks as residents vie with staff to have a go. The Space Invader, a colour model, worth £150, was generously donated by David Coren, Managing Director of Taitel Electronics, a customer of Beaumont Products.

## Spastics News

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## Integration initiative in Wales

Integration has a better chance of becoming reality if disabled children can be helped in the pre-school years. The Society's Craig-Y-Parc School, near Cardiff, has taken this maxim to heart and opened a Mother and Baby Unit — the first in Wales.

With the co-operation of Merthyr and Aberdare Social and Educational Services who provide transport and part-time sponsorship, three boys aged 2-4 now attend the school five mornings a week for 2 hours a day. All of them are severely handicapped with cerebral palsy and two are without speech. No assessment has been made except that these children and their mothers need help with the normal milestones of pre-school development.

Under the overall supervision of a trained nursery nurse, the children and their mothers take part in a programme of play and stimulation, and each child has ten minutes of speech, physio- and occupational therapy every day. Once a week they all go swimming.

Mrs Gaynor Evans, mother of Rhys, 3, is enthusiastic about the unit. "It's marvellous," she says. "We've seen a change in Rhys already. He's more outgoing, more sociable."

Before the unit opened, the only support Rhys had was a weekly trip to the physiotherapy department of Cardiff hospital.

Mrs Evans also talked of the friendly atmosphere at the nursery. "The staff never make us feel we are interfering and they answer any questions. They've been really good to us."

Maureen Fowler, headmistress of Craig-Y-Parc, is also enthusiastic. "We believe that early intervention in the form of special education and therapy can help to counteract the disabling effect of physical handicap upon a child's intellectual, emotional and social development," she says. "Early intervention of this type and degree could result in a child who might otherwise have required special education in a segregated setting being able to cope in a special unit within his own neighbourhood school." (Mid-Glamorgan is ahead of other local authorities in having many such special units.)

Mrs Fowler hopes to expand the unit. The Society's Regional Office is raising £5,000 to complete the nursery conversion, and there is no dearth of children in the area who could benefit.

As Mrs Evans says, "The younger they can go, the better."



Playing in the sandpit are from left to right, Lynn Halewood-Bauchet, staff member at Alison House, with Elaine Wheeler and Leila Russell, two of the children.

## Christmas Appeal

Central London's first short stay home for handicapped children faces closure unless £250,000 can be raised in the next two years.

Alison House in St John's Wood offers short stay places to 14 children and young adults from all over London and the Home Counties.

In 1977 the house was leased from Westminster City Council at a peppercorn rent by three voluntary organisations — The Westminster Society for Mentally Handicapped Children and Adults, The Spastics Society, and the Catholic Handicapped Children's Fellowship (Westminster Diocese). But last year the Council decided to levy an "occupation charge" of £17,250 a year.

Alison House raised its fees to £45.50 a day. Now it is caught between running at a loss and pricing itself "out of the market".

To keep the home open and to secure its future, the trustees have decided to buy Alison House, and the council has agreed to sell it for £250,000, the market price.

The Alison House Purchase Appeal was launched on 25 October at a reception held on the Martini Terrace at New Zealand House in the Haymarket. The Duke of Atholl presided, and among the guests were parents,

representatives from Westminster Council and the voluntary organisations, Westminster's Lord Mayor, Mrs Phoebe Sitwell, Peter Brooke MP — and a young man who strayed on to the terrace and generously contributed £10.

Brian Johnston, of *Down Your Way* fame, spoke from personal experience of the need for short term care and the strains that a handicapped child can put on loving parents.

"It is only possible to have a break with an easy heart if they are sure that their child will be loved and cared for in a home-like atmosphere as near as possible to where they live," he said. "The caring and loving staff at Alison House supply this need."

Chairman of the Trustees, Miss Alison Tennant OBE (after whom the house is named) urged people to give generously.

So far £80,000 has been promised, including £30,000 from the voluntary organisations, and £20,000 from the Alison House reserve fund.

There is still a long way to go.

*Donations should be sent to Richard Cox-Johnson, Hon. Treasurer, Appeals Office, 22 Churton Street, London SW1, cheques made payable to Alison House Purchase Appeal.*